

Massachusetts Universal Newborn Hearing Screening Program

2004 Annual Report

Background

Advances in technology now make it possible to screen babies for hearing loss soon after they are born. When babies with hearing loss are identified early, intervention can have a dramatic, positive impact on speech, language and overall development. Because of this, in 1998 the Massachusetts Legislature passed a law that mandates hearing screening for all newborns in the Commonwealth. Each birth hospital and birth center is required to have a program to ensure that every baby has his or her hearing screened before going home. Babies who do not pass, or miss, a hearing screening are referred to audiological diagnostic centers approved by the Department of Public Health. In Massachusetts, **1 of every 4 infants** who do not pass a hearing screening will be diagnosed with a hearing loss. The Massachusetts Department of Public Health (MDPH), Universal Newborn Hearing Screening Program (UNHSP) staff ensures that these families receive the services they need.



National Early Hearing Detection and Intervention (EHDI) Goals:

All newborns will be screened for hearing loss before 1 month of age; preferably before hospital discharge.

All infants who do not pass a hearing screening will have a diagnostic audiologic evaluation before 3 months of age.

All infants identified with a hearing loss will receive appropriate early intervention services before 6 months of age.

Consequences of late identification of hearing loss:

- Delays in speech/language and social/emotional development
- Lower academic achievement
- Increased educational costs
- Lower employment levels

Impact of Universal Newborn Hearing Screening Programs:

Universal Newborn Hearing Screening Programs have decreased the average age at which children are identified with a hearing loss. This leads to early access to intervention services and improved developmental and academic outcomes. It also gives families increased time to learn about hearing loss and communication options.

Key Program Activities:

- Convene the Universal Newborn Hearing Screening Advisory Committee
- Confirm screening results, follow-up appointments, diagnosis, and Early Intervention (EI) enrollment
- Provide parent-to-parent support upon diagnosis
- Review and approve hospital and audiological diagnostic center protocols
- Data quality assurance activities
- Provide training to approved audiological diagnostic centers

Newborn Hearing Screening Statistics

There are approximately 80,000 births annually in Massachusetts. Table 1 illustrates the number and percent of infants born in Massachusetts in 2004 who were screened for hearing loss. In 2004, birth hospitals and birth centers reported that 99 percent of infants received a hearing screening. Of those infants screened, one percent did not pass and were referred for further evaluation.

Table 1. Newborn Hearing Screening Statistics, Massachusetts, 2004^{a,b}

Newborn Hearing Screening Information Reported by Massachusetts Hospitals January 1, 2004 – December 31, 2004		
	Number	Percent
Newborns screened	78,515	99%
Newborns missed ¹	595	<1%
Newborns whose families refused screening	27	<1%
Newborns who died before screening	284	<1%

Results of Newborns Screened		
Newborns whose screening results were "pass"	77,492	99%
Newborns whose screening results were "refer" ²	1,023	1%

¹ "Missed" means that the newborn's hearing was not screened or missed due to reasons other than death or refusal

² "Refer" means that the newborn did not pass the screening and was referred to an audiologic/diagnostic evaluation center.

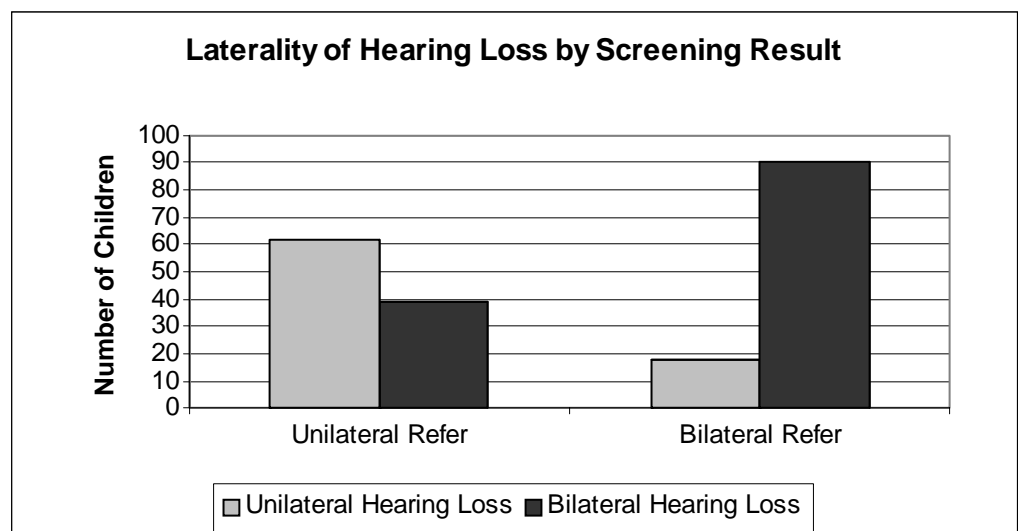
^a Data Source: Massachusetts Childhood Hearing Data System

^b As reported to The Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPHWA)

The first diagnostic evaluation should occur within one month after discharge from a birthing facility for infants who did not pass their hearing screening. Of the infants who did not pass their hearing screening, 89 percent received a diagnostic evaluation, and 82 percent received the diagnostic evaluation before three months of age.

In Massachusetts, **1 of every 4 infants** who did not pass a hearing screening was diagnosed with hearing loss. Figure 1 illustrates the comparison of unilateral hearing loss and bilateral hearing loss, by hearing screening result, for infants born in 2004. Of children who referred bilaterally and were diagnosed with a hearing loss, 83 percent had a bilateral hearing loss. Of children who referred unilaterally and were diagnosed with a hearing loss, 61 percent had a unilateral hearing loss.

Figure 1. Laterality of Hearing Loss by Hearing Screening Result, Massachusetts, 2004^a



^aData Source: Massachusetts Childhood Hearing Data System

One of the goals of a newborn hearing screening program is to decrease the average age at which children with congenital hearing loss are identified. Table 2 illustrates the number of infants reported to the UNHSP who were born in a given year and have been identified with hearing loss, as well as the average and median age at diagnosis. Median age is defined as the age at which half of all cases were diagnosed earlier and half later and is generally a more accurate indicator of the “typical” age.

Table 2. Number and Age of Massachusetts Infants at Diagnosis ^{a,b}

Year of Birth	Number Diagnosed with Hearing Loss	Median Age at Diagnosis (in months)	Average Age at Diagnosis (in months)
2002	153	1.80	2.69
2003	221	1.23	2.63
2004	225	1.15	2.32

^a Data Source: Massachusetts Childhood Hearing Data System

^b As reported to The Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPHWA)

In Massachusetts, 75 percent of children with hearing loss are enrolled in Early Intervention services. All children with confirmed permanent hearing loss are eligible for Early Intervention services. It appears that some families, with children with lesser degrees of hearing loss or unilateral hearing loss, choose not to participate.

What Families Tell Us

In 2004, the UNHSP conducted a study to measure families' satisfaction with the screening, diagnostic, and Early Intervention services they received. Over 4,000 surveys were mailed to families and more than 1,000 responses were returned.

The three groups of families surveyed included:

- 1) Families whose infants passed their initial hearing screening;
- 2) Families whose infants referred on their initial screening but subsequently passed an outpatient re-screen or diagnostic evaluation; and
- 3) Families whose infants were identified with a permanent hearing loss.

The goals of the project were to:

- Determine the levels of families' satisfaction and anxiety associated with the EHDI process.
- Determine what factors affect families satisfaction levels with the EHDI process.
- Assess whether or not a child's hearing status affects the levels of satisfaction.



More than 99 percent of families surveyed reported that if they had another child, they would want his or her hearing screened. This indicated there is strong support for universal newborn hearing screening in Massachusetts.

Overall, families reported being satisfied with the services they receive in Massachusetts. More than 75 percent of families reported being either satisfied or very satisfied with screening services. Of those families needing re-testing services, greater than 87 percent reported being either satisfied or very satisfied. For families with children who were identified with a permanent hearing loss, 94 percent reported being satisfied or very satisfied with the care their audiologist was providing.

2004 Program Highlights

- The Universal Newborn Hearing Screening Program Advisory Committee marked the sixth year of actively meeting to provide guidance on UNHSP development and progress
- Received funding dedicated to early identification of hearing loss through a federal grant through the Health Resources and Services Administration, Maternal and Child Health Bureau and a Cooperative Agreement through the Centers for Disease Control and Prevention
- Conducted a survey of physicians to develop resources for primary care clinicians in collaboration with Jane Stewart, M.D. Associate Director of the Neonatal Intensive Care Unit at Beth Israel Deaconess Medical Center and Massachusetts Chapter of the American Academy of Pediatrics Newborn Hearing Screening Representative
- Provided support and information to parents with children diagnosed with hearing loss through our Parent Outreach Specialist
- Developed strategies to ensure that Massachusetts residents born out of state receive hearing screening and follow-up services
- Provided training on newborn hearing screening to medical providers, educators and others
- Received many useful and important comments from parents on the Family Satisfaction surveys that the UNHSP will use to improve the quality of services families receive in Massachusetts
- Assessed patterns of loss to follow-up on diagnostic evaluation and EI enrollment
- Established the Universal Newborn Hearing Screening Program website to provide information to consumers and others: www.mass.gov/dph/fch/unhsp

For more information, please visit our Web site at: www.mass.gov/dph/fch/unhsp

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The Childhood Hearing Data System (CHDS) is a state-developed surveillance and tracking system designed to support the activities and operations of the Universal Newborn Hearing Screening Program. Population of the CHDS begins with the Electronic Birth Certificate (EBC), which is downloaded daily from the Registry of Vital Records and Statistics. Screening results, medical risk information, and demographic tracking information are collected through the EBC. In addition to screening results, the CHDS collects audiological diagnostic data from the 26 MDPH-approved Audiological Diagnostic Centers. These centers are required to report diagnostic exam results (with informed parental consent) for all children, born after 7/1/01, who do not pass a hearing screening, have an identified risk factor for hearing loss, or are diagnosed with a hearing loss. All diagnostic exam results are reported, including normal hearing, hearing loss, or missed appointments. Additionally, staff has received legal access to link to the statewide EHS to ensure that children with hearing loss receive Early Intervention services.